

The live experience of people suffered by leprosy

Mukhlasin Mukhlasin¹, Tukimin Sansuwito², Asita Elengoe², Andiko Nugraha Kusuma¹

¹Department of Public Health, Faculty of Health, Universitas Faletehan, Banten, Indonesia

²Department of Biotechnology, Faculty of Health Science, Lincoln University College, Petaling Jaya, Malaysia

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ABSTRACT

Leprosy, unlike other high-fatality diseases, is a long-term, chronic illness that can cause long-term disability. People's experiences with leprosy in Indonesia, indicating a need for responsive leprosy services to meet the wide range of requirements, including care for those who are not formally afflicted with the disease. This study aimed to explore live experience of people affected by leprosy in the community in Banten province, Indonesia. This study employed inductive phenomenological research methods with a semi-structure interview. We used snowball sampling, and people who could not communicate or did not want to take part in the study were not included. The majority of the participants were below 45 years, and 21 were male and 19 were female. Among total participants, only 15% could not read and write. The data were examined using Colaizzi's phenomenological analysis, which involves collecting and analysing data in parallel until no new information is acquired. We established trustworthiness in qualitative studies. The following themes emerged from this study: i) public understanding about leprosy; ii) psychological response; iii) perceived stigma; iv) health seeking behavior; and v) leprosy's impact on economic condition. This study identified the meaning of leprosy patients' lives through their own voices. People who have leprosy should also get spiritual help, coping skills, and training in self-care skills.

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Corresponding Author:

Mukhlasin

Department of Public Health, Faculty of Health, Universitas Faletehan

Raya Cilegon Street No. Km. 06, Daydreaming, Kramatwatu District, Serang Regency, Banten 42161
Indonesia

Email: sintong212@gmail.com

1. INTRODUCTION

Leprosy is a chronic infectious disease caused by the bacterium *Mycobacterium leprae* that continues to be endemic in more than 20 low-and middle-income countries [1]. According to the WHO, almost 95% of new leprosy cases in 2018 occurred in 22 priority countries. Leprosy cases are mainly concentrated in India (60%), Brazil (13%), and Indonesia (8%) [2]. According to a previous report, 7% of the over 200,000 new cases of leprosy discovered each year occur in individuals who have already established grade 2 impairments [3]. Indonesia is responsible for almost 17.02% of newly confirmed leprosy cases worldwide [4]. During the 2017/2018 reporting period, the prevalence rate for new-case detection (NCDR) was 0.70 per 10,000 persons, with an annual rate of 6.08 per 100,000 people [5]. The province of Banten reported a NCDR of 0.78 per 10,000 population, and annual rate of 7.57 per 100,000, which was higher than the national NCDR [5].

Leprosy, unlike other high-fatality diseases, is a long-term, chronic illness that can cause long-term disability [6]. Leprosy is a disease that mostly affects the skin and peripheral nerves. Nerve damage can affect the sense, motor, and autonomic functions of the nerves, which can lead to disability [7]. Approximately two million people are affected with leprosy-related disabilities [8]. Many patients with leprosy face social stigma

as well as the disease's clinical symptoms, and this stigma can last long after medical treatment has ended [9]–[11]. Community perceptions and attitudes about leprosy patients are an important and unique indicator of how a society stereotypes leprosy [12]. In Thailand, about 55% of people thought that living in a community with people who had leprosy was a shame or embarrassment [10]. In Western Nepal, 51% of community people believed that leprosy patients conceal their diseases because of fear of social rejection [9]. In Indonesia, stigmatization of leprosy is a major issue, which makes it difficult to diagnose and cure leprosy patients [13], [14]. The stigma associated with leprosy affects many aspects of their lives, including marriage, social contact, and employment [12], [15].

According to our preliminary study conducted to 15 patients diagnosed with leprosy found that most of people with leprosy were unemployed, low education level. They also reported difficult to get work because they personal appearance and disability. To fullfill their basic need, most of them relied on helping from family members or neighbor. Most of the lived-in isolation space and has limited social interaction. They eat three times a day without considered a well balance nutritional intake. Regarding their living condistion, most of them living in the room with size around 2x3 meter, had little access to clean water. The most of them were living with leprosy for more than two years.

Numerous studies on leprosy have been conducted in Indonesia, with a particular emphasis on biomedical issues [16], [17], stigma reduction [18], and risk factors [19]. Peter and colleagues [20] emphasized the wide range of people's experiences with leprosy in Indonesia, indicating a need for responsive leprosy services to meet the wide range of requirements, including care for those who are not formally afflicted with the disease. In Indonesia, previous studies related to leprosy more focus on exploring biomedical aspects [21], [22], stigma reduction [18], and risk factors [19]. Highlighted the diversities in people's experiences with leprosy in Indonesia that indicate a demand for responsive leprosy services to serve the diverse needs, including services for those formally. There is also a lack of studies deeply understanding the dynamic of social and environmental aspect among leprosy. To better inform healthcare policy, it is critical to explore leprosy in its wide variety of meanings and experiences as experienced by persons living with leprosy [23]. This study aimed to explore live experience of people affected by leprosy in the community in Banten province, Indonesia.

2. RESEARCH METHOD

2.1. Study design and participant

Phenomenological research was utilized to investigate the living experiences of people with leprosy. This study was carried out in a public health center in Banten, Indonesia. This study employed Colaizzi's phenomenological method of inquiry as its methodology. Colaizzi's method of analysis was expanded upon as a result of subsequent study in which participants were given the opportunity to communicate their experiences using common language [24]. These 'expressions of life' comprised art, music, poetry, and metaphor as symbolic representations as a means for individuals to articulate their experiences.

2.2. Ethical considerations

The institutional review boards of the affiliated university accepted this study (No. 2032/ETIK/UF/2021). We informed study participants about the study's goal, protocols, and information storing and deletion practices before the study began. We also told the potential participants that their data would be kept private, that recordings would not be used for anything else, that they could refuse to answer certain questions, and that they could stop taking participate in the research at any time. People who volunteered to take part in this study provided us with written informed consent. In order to maintain participant anonymity, no personally identifying information was included in the study's interview transcripts, and none of the data was made available to anybody outside of the research team.

2.3. Research procedures

Focus group discussion using a semi-structure interview were conducted with the participants' consent using a digital recorder. The procedures used to collect data were as follows. Prior to the interview, we discussed the study's purpose and introduced ourselves to the participant, then confirmed if they could reply by cell phone or in person. For those who agreed to participate in the study, we scheduled the day, time, and location of the interview and carried out the interview as scheduled. An open-ended question, starting with the opening question, "tell us about your experience as a person impacted by leprosy." Participants were then urged to freely elaborate on their own experience, including facts about initial infection, individual and interpersonal perceptions of leprosy, medical interventions and daily activities. The authors developed questions based on previously published literature [24]. There was a total of fourty participants agreed to join in this study. It took between 30 and 90 minutes for each interview to complete. Non-verbal events such as laughter, quiet, and nodding were incorporated in the transcription of the recorded interviews. Researchers conducted interviews until no new ideas could be gained from the information collected. The interviews were place between December 2020 and May 2021.

2.4. Data analysis

Colaizzi's [26] method was used to analyze the data. First, we recorded all participants' statements and reviewed them frequently to gain a deeper understanding of their experiences. Then, formulated meanings were grouped into themes. Then, we synthesized all of the findings into a comprehensive narrative explanation. Then, using unambiguous phrases, we were able to determine the underlying basis of the experience. Finally, we checked to see if the findings were representative of what the participants had to say by polling them to see if they agreed with the findings. The findings were presented in a vivid narrative style using data which most consistently illustrated the study's themes [25].

2.5. Trustworthiness

To ensure the validity of the present study's, we reviewed and examined the obtained data. Throughout the process, we asked participants to validate our interpretations and depictions of their personal experiences. Additional text and non-textual data were also used to complement or compare interview content. Interview data were examined for content validity by reading and rereading data that had been reorganized from participants' answers to questions. Testing was undertaken by authors that have a lot of experience in qualitative inquiry by comparing interview content to data that had been reorganized and categorized.

3. RESULTS

Table 1 shows that a total of 40 participants from four different FGDs were included in this study. The majority of the participants were below 45 years, and 21 were male and 19 were female. Among total participants, only 15% could not read and write. The major theme found in this study were: i) general knowledge about leprosy; ii) psychological response; iii) perceived stigma; iv) health seeking behaviour; v) leprosy affected economic situation.

Table 1. Characteristic of studied participants

	FGD 1	FGD 2	FGD 3	FGD 4
Age				
< 45 years	7	6	5	5
>45 years	3	4	5	5
Gender				
Male	5	4	5	7
Female	5	6	5	3
Education level				
Low education	6	5	5	4
High education	4	5	5	6

3.1. General knowledge about leprosy

Several participants said that they had no prior knowledge of leprosy, and some even asked the interviewer questions, such as:

"I'd like to ask... Is it accurate that leprosy can have a biological effect on humans?" It was as if everyone's hands were on the table." (P13)

"What does it actually matter?" (P04)

"I am not quite understood the meaning of leprosy and why it could be happened to me?" (P15)

Participants frequently expressed leprosy as "red and white rashes," "facial got red," "nodules," "swollen veins," "you cannot sense nothing when beaten," "ulcers," "arms shrink," and "impaired physical state". People who had been infected with leprosy reported various symptoms such as "hot," "itchy," and "pain." Leprosy patients have remarked that it is their dark skin, not the disease, that makes them feel inferior.

"I believed the lesions had developed to the point where they were ready to be picked like fresh fruit. That rash appeared to be quite mature, much like the black nails on a mature mango." (P11)

"I was surprised since I had darkened. I used to be very white, but has since darkened." (P05)

3.2. Psychological response

All participants expressed frustration and dread regarding the earliest symptoms of leprosy, as well as fear regarding their own bodies deforming grossly beyond their control. They noticed their sickness in physical deformity. Additionally, leprosy poses a heavy financial burden on the family. The condition worsened as a

result of mistreatment and confinement to the house. Patients with leprosy also had to deal with the psychological burden of finding family members rejected because of their illness.

"It grew bluish and fat because of the swelling of the face, which caused deep wrinkle-like lines to appear. The only thing that made me unattractive was the size of my eyes." (P11)
"It was only after food was delivered to the room that I could leave the house." (P15)
"If I truly desired to go out, I would have to do so at night." (P10)
"Everything went wrong because of me. In many ways, my younger siblings and I share the same struggle. We used to have a common well in our neighbourhood, but the people in our neighbourhood refused to let us drink from it." (P05)

People affected by leprosy frequently faced shame and a lack of self-confidence.

"My skin turned pale, and I remained confined to my house for the rest of my days, unable to participate in any outdoor activities." (P05)
"I am different from others, and my life will continue in this manner, which makes me feel humiliated." (P13)

3.3. Perceived stigma

People with disabilities encounter stigma, which they believe must be accepted, while concurrently expressing rage and sadness:

"I had the idea that leprosy could not be treated and that people will no longer be friends with me when nurse declined to shake my hand." (P02)

Participants were unable to disclose their illnesses to anyone. The fact that individuals were concealing their illness status had an impact on their health-seeking behaviour and decision-making. Despite the fact that concealing the disease was considered more usual in the past, leprosy patients were considered to reveal their illness to close friends or family members.

"In order to receive medication, I must travel to the hospital in secret, whereas others choose to sit [at home] and wait for the disease to pass." (P09)

Some people were frightened to go for fear of becoming infected. In other cases, people were hesitant to go because of the unfavourable attitudes of the community towards leprosy, even if they were aware that transmission could not occur in the first place.

"The health worker is still terrified, concerned..., and many are still." (P04)

3.4. Health seeking behaviour

The majority of leprosy sufferers sought medical assistance from public health services. Several people expressed concern about the difficulty in obtaining access to public health care. They needed medical attention but couldn't afford public transit from their house to a health care facility. Leprosy patients frequently underestimate the severity of their symptoms, delaying clinic visits.

"I thought it is just like scabies, so I just put the medication as I know." (P08)

"I went to public health services to ask for help if I feel severe condition, but If I can handle it by myself, then I just try my own traditional therapy."

Several respondents also came to a shaman to get help and treatment for their disease.

"I was told by some friends to go and see a shaman. I forgot her name and she does not solve my sickness or cure it, but asks for more funds." (P09)

3.5. Leprosy affected economic situation

Due to physical constraints, some of the participants were unable to do their previous jobs, such as producing furniture. Participants stated that if leprosy patients had been educated, trained, and possessed the physical ability to execute a job, they would have had little difficulty finding work. Nevertheless, other participants indicated definitely that leprosy patients would be denied work if they exhibited physical deformities. Jobs were assigned based not only on the ability to complete the work, but also on the broader consequences of social stigma, such as how consumers would be prevented from visiting their store.

"If I have skills and experience, I will certainly be granted the job. However, if they have physical disabilities or are disabled, getting a job can be difficult." (P17)

"Even I can do the job, they might not be favoured due to obvious impairments, taking into account how customers will react [for example, in a restaurant]." (P06)

4. DISCUSSION

The finding regarding general knowledge about leprosy indicated that several participants said that they had no prior knowledge of leprosa. They also have a lack of understanding about leprosy's diagnosis, etiology, and transmission routes. The assumption that leprosy is a highly infectious disease that may be transmitted by coming into contact with the same objects that leprosy sufferers have come into contact with is alarming [13]. Many patients are left with disabilities, blisters, broken skin, and amputated limbs even after treatment. Leprosy patients were more likely to accept their physical deformities. Medical leprosy is a disease that causes severe suffering over an extended period of time and manifests itself in a variety of ways; it urgently requires state-of-the-art treatment at general hospitals in big cities [26]. Increased awareness of the leprosy issue among those directly touched, society at large, and health professionals continues to be a critical objective for leprosy care [27].

All participants expressed dissatisfaction and worry about the initial leprosy signs and fear about their own bodies deforming. Leprosy patients also faced the psychological strain of familial rejection. This shows that even if governmental or organizational efforts to eliminate leprosy prejudice are implemented, the deeply embedded discriminating and excluding attitudes do not simply alter. Patients affected by leprosy developed an entrenched habit of isolation in other remote areas, generating the dilemma that hospitals trained to address people affected by leprosy actively and professionally are largely unfamiliar with the disease [28]. There is a widespread misconception that patients with leprosy are contagious, even among health care professionals who may have never worked with patients [29]. Even while several techniques for reducing stigma, such as rights-based therapy, have demonstrated promising outcomes, a more practical approach that integrates components of community involvement should be combined with them. The basic structure for community engagement has been successfully used to control and eradicate other diseases and may be changed to build stigma reduction techniques for leprosy. Engaging community members and patients in efforts to reduce leprosy stigma is a better option than a vertically integrated program. Continuous promotion and reform on the point that the disease is not communicable after treatment are required to overcome the process of stigmatization [30].

People with leprosy, on the other hand, suffer merely from the disease's scars and handicap; the consequences of prejudice, discrimination, and bad isolation policies, such as forced sterilization surgery, have not erased from society. This is in accordance with prior study in Indonesia that found concealing the disease to be the most stigmatizing [31]. Those who have been infected with leprosy require a support structure that may help them accept their situation and live happily for the rest of their lives. Fear, humiliation, and low self-esteem are also common emotions for people affected. Furthermore, they are unable to live while keeping a strong relationship with their families, and as a result, there is no machinery for easing anxiety and fear of death in their environment. Individuals affected by leprosy were accustomed to appeasing and accepting their cruel lives, as well as to protracted societal prejudice and ostracism. Thus, they had a tendency to avoid asserting or demanding their own rights [32]. Further research is needed to make sure that the mental health impact of leprosy is taken into account when determining the burden of the disease, and to help relieve this burden. Thus, healthcare professionals, especially nurses, must provide programs such as counseling and recollection therapy to help victims recognize and accept prejudice and ostracization. People who have leprosy should also get spiritual help, coping skills, training in self-care skills, and help from people who know them [33].

The majority of leprosy sufferers sought medical assistance from public health services. Several people expressed concern about the difficulty in obtaining access to public health care. They needed medical attention but couldn't afford public transit from their house to a health care facility. Delay in care and the resulting damage are catastrophic consequences of hiding the illness. Adolescents in India, for example, were hiding their disease and delaying therapy owing to societal stigma [34]. Leprosy patients had difficulty working owing to sequelae like physical impairment. Economic challenges may make it harder to obtain financial assistance for medical services [35]. For leprosy patients with dependents, steps to improve their quality of life and to give emotional and medical assistance are essential. A sustained national effort is required to discover new and effective techniques of relieving their suffering in the future.

5. CONCLUSION

Finally, we recognized the meaning of leprosy patients' lives through their own voices. People affected by leprosy highlighted the lack of general knowledge about leprosy, psychological response, perceived stigma,

health seeking behaviour, leprosy affected their economic situation. As a result, public policies for dealing with diseases aggravated by socioeconomic inequity may be better defined.

In light of the findings of the study, we propose the following recommendations for nursing practices in general. First, this study focused on a small group of leprosy patients in one province. Thus, more research may be needed on people who have leprosy in another province. Second, we recommend that an operating system be developed and that the number of health workers caring leprosy patients be increased in order to improve their access to care in rural areas. Third, sustained promotion and modification are required to overcome the stigma of leprosy in the community.

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BIOGRAPHIES OF AUTHORS



Mukhlasin He is a doctoral student at Health in Science, Lincoln University College, Malaysia and served as faculty member at Department of Public Health, Universitas Faletehan, Banten, Indonesia. He can be contacted at email: sintong212@gmail.com.



Tukimin Sansuwito He is a senior Lecturer and researcher on Nursing and Public Health at Departement of health science, Faculty of Applied Science, Lincoln University College, Malaysia. He can be contacted at email: tukimin@lincoln.edu.my.



Asita Elengoe She is a senior Lecturer Lincoln University College, Selangor, Malaysia. She graduated from faculty of Ph.D. in Bioscience from Universiti Teknologi Malaysia. She can be contacted at email: asita@lincoln.edu.my.



Andiko Nugraha Kusuma He is the Chancellor of the Universitas Faletehan. He can be contacted at email: andiko_nugraha_kusuma@uf.ac.id.